



Gannet's Journey

Planning & Creating a Legacy for Life

Amy Hosa, mother

Alex Gallego, Service Coordinator

Gannet's Journey



10th Anniversary of Key of G

AMY: A PARENT PERSPECTIVE

- **A Look Back...**MWS Milestones and Events
- **Person Centered Planning**

ALEX: A STAFF PERSPECTIVE

- **Supported Living**

Staffing, Training, Expectations, Advocacy, Implementing the PCP, and Task Analysis





A Look Back Milestones & Events

Sitting Up to Walking

Still floppy at 2



Sits up by 4



First Steps at 8



AFOs
at 3



Crawls
at 5



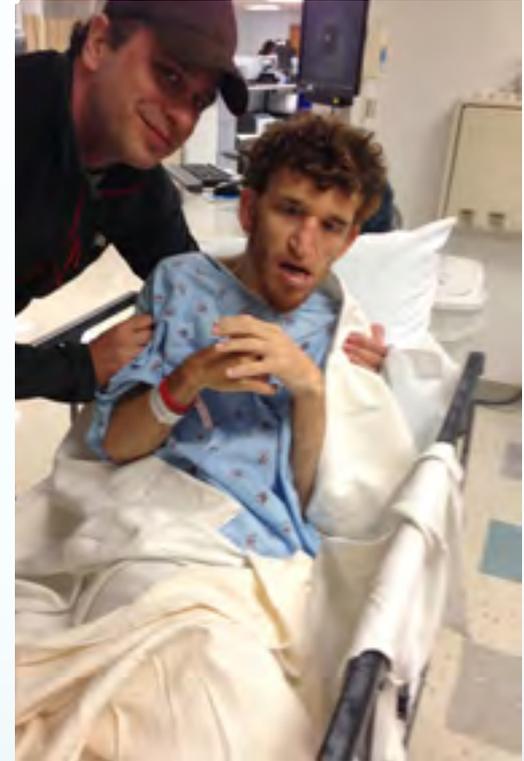
Walker
At 6

Medical & Seizures

Colostomy Surgery at 1 mo and 4 yr



Cataract Surgery at 23



Seizures:
Grand Mal at 6
Frontal Lobe at 30



Dental
at 35

Self Help Skills

Bottle at 9 mo



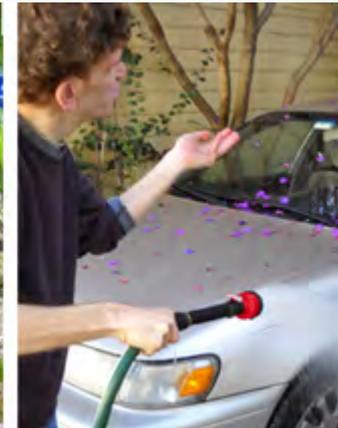
Spoon at 3 yr



Sets Table in Teens



No Diaper at 9 yr



Fine Motor: Holds onto objects in Teens...

Early Communication...ONGOING

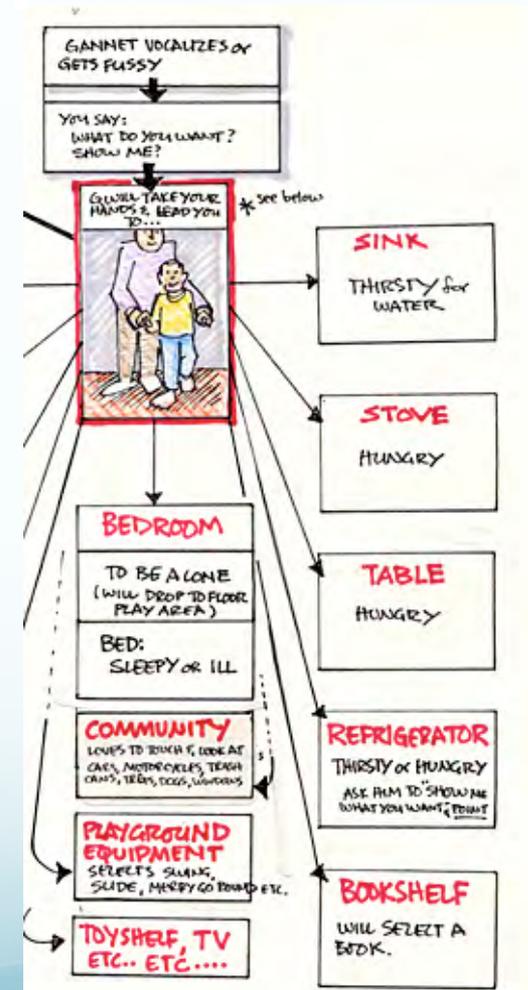
Gestures at 4



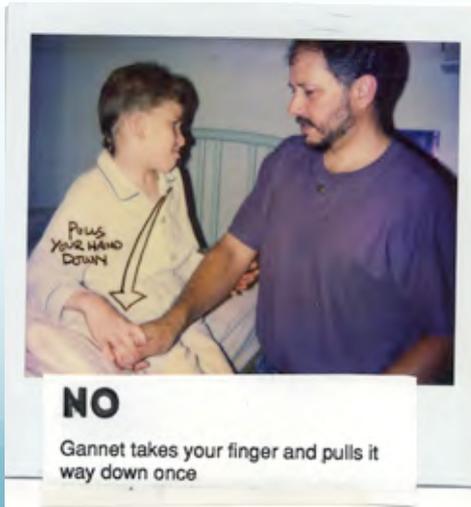
Photos+Icons at 4



Leading at 4-5



Tactile Signs at 8

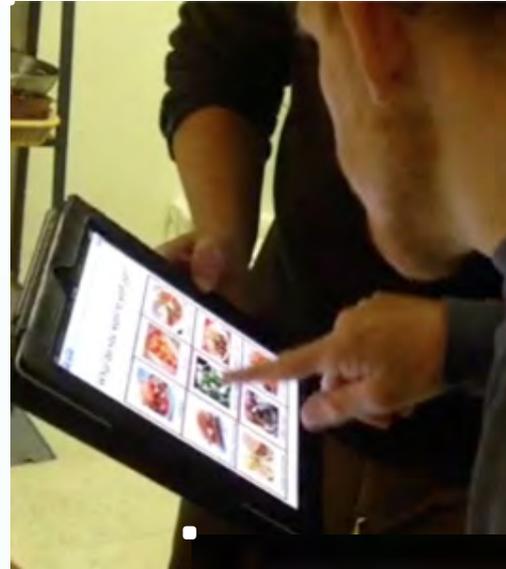


Icons at 6



Augmented Communication

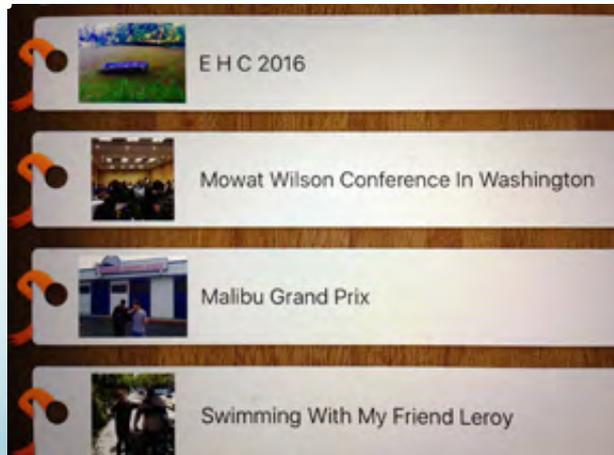
ProLoQuo General conversation



Visual Creator for Menus

Doodle Draw Notepad to Write word choices

Pictello for stories



Social Skills

Recognizes parents
By VOICE at 2



Recognizes parents
by SIGHT at 4



Vocalizes
with & takes
interest in
peer friends
at 33





Introduction to Person Centered Planning

First Person Centered Plans



I'm leaving home!

PARENT MADE CARE GUIDES

Childcare, Summer Camps, Hospital Stays, Overnights at Grandma's

LEISURE TIME

Social Skills and Game Playing

Encourage Gannet into participatory play and group activities. He might whine at first, or act distracted, but he usually gets enthusiastic about participating once the fun starts. His responses are slow, but encourage or help him to focus, take his turn and be a part of the action.

- Kickball is a favorite
- Horseshoes
- Ball darts
- Throwing the ball for the dog
- Playing IN the dog house
- Playground play on swings & climbing structures
- Water play, another favorite
- Simple table-top board games (with animal/d players)
- Getting teased and tickled is a favorite



YES and NO

TALK TO GANNET CONSTANTLY

... and engage him in conversation by asking him "Yes" and "No" questions. This is very important.

Gannet has intelligence, and his teacher is always after everybody to talk to Gannet, and get him involved, explain everything to him, keep him focused and insist on his participation in communication and activities. *No free ride for this kid!*

Gannet can be a joker, so be forewarned of his sense of humor or teasing. He starts to snicker if he's pulling your leg.

UNCLEAR HAND & ARM MOVEMENTS

• Sometimes Gannet will shake your hand then pull it down. Tell him you're confused, ask him could he please try again.

• **BE POSITIVE**, don't tell him he's wrong, but thank him for trying, it's just a but confusing for you, so he needs to do it again.

IS GANNET CONTRADICTING HIMSELF?

If you get a confusing or conflicting yes/no response...think about some creative questions you could ask to further clarify the communication.

For example:

Do you have to go to the toilet? "YES": ...then you sit him on the toilet and he doesn't go, so you ask: Do you have to pee? "NO." Gannet has just contradicted himself...so you ask: Do you need help? "YES". ...Do you need water? "YES." So, you run the water and he pees.



YES

Gannet takes your finger and shakes it up and down



NO

Gannet takes your finger and pulls it way down once

Transition to the Adult World

GOAL: TO GATHER ENOUGH INFORMATION FOR ADULT DAY PROGRAM & SUPPORTED LIVING to SUCCEED

PROFESSIONAL TEAM

- Medical and neurological reports
- High School IEP and goals
- High School Transition Report: from entire staff

PARENTS

- Overview of G's home life
- Spreadsheet: daily activities, 24/7
- Copies of ALL Care Guides

ADULT AGENCY

- Interviews
- Intake Assessment & Review
- Plan, Funding, Staffing Needs
- Mission Statement
- Business as usual

What Went Right & Wrong

A person's adult life
is only as good
as their staff.

Staff Reinvent Gannet

“Oh, I just do everything for him, he’s much happier. Poor soul, life is too hard.”

“Homeless people are attracted to Gannet. He has lots of friends.”

“Gannet is so fragile, I’m afraid to go out, so we just stay in and watch tv.”

Agency Reinvents Gannet

“Gannet’s new staff picks are bottom of the barrel, because skilled staff won’t work for Gannet, he’s too difficult... That’s the way life is going to be for someone like him.”

– GANNET’S SERVICE COORDINATOR

What is a Person Centered Plan?

Nobody
knows everything
about anybody

Nobody
has the right to
reinvent anybody

Gives voice to individual's point of view

Reflects interests, preferences and strengths

Defines entire life

Describes supports

No template

NOT A GUARANTEE

One of many documents used by staff and agencies to determine appropriate staffing, services and natural supports

Giving “Voice” to the Individual

Gannet’s “Voice”

- An **interpretation** of his personal preferences
- Reviewed w/ Team Approval

Other Voices:

- Descriptions of issues and services on G’s behalf
- Reviewed w/ Team Approval



Person Centered Plan

Gannet Hosa-Betonte, 2014

A Special “Thank You” for 2014 PCP content:

Gannet Hosa-Betonte, Amy Hosa, Alex Gallego, and Bennet Tglio, along with edits and comments from Chris Jannini, Chris Bonfiglio and Socorro Gallardo. This revised PCP 2014 retains text and ideas from previous versions with contributions from Colter Jacobson, Donal Moser, Katie Edmonds, Steve Dexter, Ryan Wilsey, Mark Eriksson, and observations and words of wisdom from all of Gannet’s past teachers, mentors, therapists, friends and family.

G's Person Centered Plan

Table of Contents

- Introduction to Working w/G
- What is my PCP, Your Role?
- Who is Gannet
- How You Interact with ME
- My People
- Vacations and Holidays
- Supported Living Services
- Day Program & Life Skills
- My Bucket List
- Mowat Wilson Syndrome
- Medical Issues
- Behavior
- Motivation & Learning Modality
- Gannet's and Your Safety

WHY IS A PCP IMPORTANT?

HOW IS IT USED?

It's My Life, I Get to Choose...



SUPPORTED LIVING CHOICES

- Where I live, who I live with
- What I do, how I do it
- What I eat, where I go
- My staff, my friends, even my love life
- My preferences and dreams

...by making
appropriate decisions

Who am I?

- Intelligent
- Capable
- Inconsistent
- Cooperative
- Love new ideas

Who is Gannet?



I Am an Intelligent and Capable Person.

I can also be inconsistent in my abilities because of neurological interference, so please be patient and understanding.

I appreciate having the opportunity to have choice in the decisions and outcomes of my daily life.

I need augmented communication systems to speak, and have always have things to say.

I understand conversations, and I have opinions to offer.

I understand what is read to me, whether it's a dinner menu or museum caption.

I have the ability to cooperate, and act socially responsible.

I like having books read to me. Books I've read are diverse, from Dylan Thomas' *My Life as a Dog*, to Tom Swift adventure stories, and many diverse topics fact or fiction.

When introduced to a new idea or subject that I find interesting, I enjoy researching more information about it, and talking about it.

WHAT IS A GANNET?



In case you're wondering, a Gannet is a big beautiful water bird that lives in large colonies on cliffs in the British Isles, New Zealand, and other places too. I was named after the bird.

I am a Soundscape Artist



CONTINENTAL DRIFT
Gannet Hosa-Betonte, Composer
Alex Gallego, Producer and Arrangements

1. G's New Song
2. Gannet Is Knocking
3. Funky G
4. Yes, Yes, No...
5. A G and a Bop
6. Amah's Song
7. Car Song
8. Car Wash

"CAR WASH" music video by André Marty and all songs are online.
www.gannetsnotes.net

SEE MORE STORIES and PHOTOS INSIDE BOOKLET
Music © Graphics © Gannet Hosa-Betonte 2016
Cover & Back Photo by Alex Gallego • Graphic Design by Amy Hosa

This CD was recorded over the course of two years. It incorporates both real instruments, such as guitar and bass played by Alex, with digital sounds by Gannet playing multi-layered midi instruments, synthesizers, and various keyboards. G's music is proof that an inspired and talented musician - one who happens to be disabled and follows his own muse - can create beautiful & interesting songs by using musical technology.

CONTINENTAL DRIFT
GANNET HOSA-BETONTE

Personal Philosophy & Values



This list represents the backbone of the lifestyle choices, philosophy, and values that I experienced growing up within my family. Friends and staff need to maintain opportunities that enable me to communicate and experience these lifestyle and ethical choices, and document new ones.

Where Do I Come From?

- My family's values and philosophy are my roots

- Friends and family are very special. Have a big heart.
- Be a good neighbor.
- Have a social conscience, respect and tolerance for others.
- Volunteer for good causes. Little steps add up. Work for peace.
- Act responsibly. Be honest. Be responsible for yourself. Respect yourself.
- Live within your means. Be frugal, but spend some on frills too.
- Practice generosity. Don't be greedy.
- Exercise your freedom of speech when so moved.
- Obey most rules. But, question authority and power if it doesn't seem right.
- Equal rights for all people.
- Be good at what you do.
- Find happiness and fulfillment in your creativity. Offer something good back to your community and the world.
- Love and laughter go a long way.
- Be flexible and accommodating. Cooperation is a very good skill.
- Make intelligent decisions. Ask intelligent questions.
- Make change. Have patience for change.
- No religion.

Defines Preferences

- I do not want to live a “cookie cutter” life
- What I like
- What I don't like

How I Look



I have worn a beard, and sometimes I'm clean-shaven.

I want to look hip and intelligent, and be dressed appropriate for the occasion.

I drool – my apologies – so keep a handkerchief handy.

I want to be clean, and not be seen with drool, food stains or dirt on my clothes.

What Makes Me Happy. What Makes Me Upset



I'm happy when. . .

I'm with people I really like and they take time to communicate with me.

I am understood, and my communication is clear.

I feel good about what I'm doing.

Playing music. Music is my feel-good vibe.

You notice I'm weary, and ask me if I want to take a break, and rest awhile.

I get upset when. . .

I can't communicate what I need, or intend to do. It's damn frustrating!

People talk down to me, or talk about me as if I'm not there.

People lead me around like a dog, talking to me but not expecting me to talk.

People baby-talk to me.

People take over my life, as if I'm an incapable invalid.

How I Live MY Life

- Where I live
- My home
- Comforts & cozy
- What staff do NOT do in my house



San Francisco is My City

I like to be out, and love the sounds and motion of living in a city. I love the energy of it all.



I like the adventure of riding on public transportation - the busses, streetcars and BART. I like the variety of places to go in the city – like going to a museum or walking in the cold surf on a beach or having a picnic in a warm-sunny park, or even just getting out of the house to run an errand to a store nearby. I enjoy going out to all the free concerts, street fairs and events. I also have memberships to both fine arts museums, the DeYoung and the Legion of Honor, and go to evening adult events at the Exploratorium and other venues. Just about any month, there are concerts and events given by folks that tickle my soul, like the Thing-a-ma-gig music makers, or Street Dancers and Pamela Z. San Francisco is a great place to live, and a great place for me to pursue my music and art too. In San Francisco, there is no excuse to find me sitting at home because there's nothing to do!

The Fillmore is my Neighborhood



I live in a huge apartment complex in San Francisco's Fillmore District. I prefer to live in an urban neighborhood that is alive, and has all the amenities within a short walk, like bus stops, grocery stores, restaurants and general shopping. The Fillmore neighborhood has all the above, plus a recreation center with swimming,

Highlights Skills and Staff Interaction

“Gannet-centric” examples of

- What I can do
- What YOU can do for me

How I Communicate



How We Talk to Each Other

HOW I TALK TO YOU: I have problems with instigating communication. I might begin to vocalize sounds, or point, or grab your hand to lead you somewhere. I hardly ever walk over to my iPad to use it spontaneously. ***I rely on you to be proactive: to ask me if I want my iPad or to show you something, to ask me questions about what's on my mind – is it something general, or what I need at the moment.*** By using a variety of communication systems, I express words and articulate ideas. I will point to pictures, symbols and words to string thoughts together. I can be very specific. You need to be very patient. If we don't succeed in a clear communication, you need to alter the approach and try again. Note: A lack of spoken language is typical of people with Mowat-Wilson Syndrome.

HOW YOU TALK TO ME: I understand you. Please talk to me like an intelligent adult. Besides what you speak to me, I can read and understand individual words and picture symbols. You can also use the iPad apps, or you can write key words on a piece of paper to give me “communication tags” that I can use when I respond back to you about a particular subject. You might need to use a mix of these methods – draw a picture, use existing picture icons, written key words, photographs, pointing to objects, etc that help illustrate what you're talking to me about.

Everybody who works with me needs not only extensive training on my communication systems, but also training on how to interpret my conversations.

BEWARE of MISINTERPRETATION: The success of my communication depends not only on my choice of words, but also on their interpretation by you, the person listening. Sometimes my speech is cryptic, or confusing. *(YOU should try making intelligent conversation with just a few hundred symbols!)* Facilitating and interpreting my communication is complex, please have patience to ask questions and confirm intent, so you really get what I'm trying to say. *See the Task Analysis section: Communication.*

INCONSISTENCY: There are days when I am spot on, clear and concise in my pointing and choices, and others when I just flip the iPad away. It is sometimes hard to discern whether I'm simply confused and having a bad day, or I'm just

Offers Tips

COMMUNICATING



I have problems with instigating communication. I might vocalize sounds, or point, or grab your hand to lead you somewhere, but hardly ever walk to my iPad to use it spontaneously (*so, please, encourage me to do so more often!*). I usually rely on you to be proactive and get my iPad out, to ask me questions about what's on my mind, or what I need at the moment. I understand everything you say, and I enjoy conversation. I can speak if you help me use the iPad communication apps. I point to and touch the icons that have a digital voice. I also point to words on the screen or words that you write on paper, will point to objects, and can lead you to people, places or things that I'm talking about. *More details are in the "How We Talk to Each Other" section, and task analysis videos.*

Highlights Issues

- Abilities and Challenges
- Behavior
- Communication
- Personal Safety

Behavior

For behavior intervention techniques, see the Task Analysis section, "Behavior Modification Tactics"

Positive Social Behavior and Affection

PREFERENCES: I can communicate preferences for people I want to get together with, when I want to be social or when I want to chill. I enjoy seeing my friends. I like to do group activities. And, believe me, I have people that I don't care to be around as well, and hopefully you'll understand my signals.



THE TACTILE WORLD: I build relationships with people through touch and sound, more so than through eye contact. Touch is a key a building block in my world.

PERSONAL GREETINGS: I like to get and give a pat on the shoulder, or a hug as a greeting. Sometimes I have a mannerism, for lack of better words for you StarTrek fans, that is like the Vulcan mind meld. We touch foreheads and sustain the pose for a moment. Another greeting – a special one for favorite people – is the raspberry, where I spit in your face, smile and laugh. I'm repeatedly told that a raspberry is not socially acceptable, and should be discouraged.

HUGS and BACK SCRATCHES: Among family and close friends, I also give a great hug in the morning, to say goodnight, etc. I enjoy a firm, sustained hug from my family and friends, and will embrace them with both arms and pat them on the back to show my affection. At bedtime, I might fling your arm over my head to my back, as this is a request for a back scratch or back rub - for as long as you have time.

Medical Issues

- Communication
- Diagnosing
- Taking Action
- Medication
- Colostomy

Medical Issues

General Health and Symptoms

I am in good health. I have a yearly check up with my medical doctor and neurologist, yearly lab tests, and routine eye exams for pressure.

DIAGNOSING PAIN, SICKNESS and IDENTIFYING SOURCE

For serious painful illnesses and injuries (like an ear infection or slipped kneecap), or bumps from bad falls, I almost never cry, and don't necessarily point to or grip the pained or hurt area. Rather I shake and moan (and people think I'm having a seizure). If it's an invisible pain or injury, it's only through careful observation and physical examination, along with using my iPad communication symbols and body page for me to explain, that one can figure out what is going on, and how severe it is. Diagnosing my symptoms can be confusing.

WHEN IN DOUBT – TAKE ACTION

If I am showing a symptom of pain or illness, consider that I need attention, and you need to take action now. My health insurance, Kaiser, has a medical advice line with an advice nurse. Call it ASAP. They can give you a home remedy, or make a drop-in appointment to see a doctor if needed – day or night and weekends, 24/7. Document all illnesses, injuries and any calls to doctors and prognosis. Alert your supervisor and my supported living coordinator of all the above. If you need to take me in to a doctor, also please call my mom to let her know what the prognosis is.

MEDICAL ADVICE & APPOINTMENTS: 415-833-2200 (open 24 hrs)

If a life-threatening medical emergency, call 911.

LINK: to listing of Gannet's doctors and contact info.

The Colostomy Bag



A detailed colostomy care guide is in video and print. This is just an overview.

I've had a colostomy bag since I was about 4 weeks old, so it's like a second skin. I do not pull it off, although it gets itchy and I scratch.

G's Expectations for Staff Defined

- Hands off
- Facilitator
- Assistant
- Caregiver

How I Want YOU to Interact With Me

Different Levels of Support and Care

Upon first meeting me most people make the mistake that I'm helpless, and they treat me like a simple-minded invalid. Let me cut to the chase and give you some definitions to enable you to interact with me as an intelligent, capable and semi-independent person, who needs different levels of support and care depending on the situation.

Definitions of Facilitator, Assistant, and Caregiver

To facilitate is "to make something easier, or easy to do".

A facilitator "aids or assists in a process, especially by encouraging people to find their own solutions to problems or tasks".

To assist is "to help somebody to accomplish something".

An assistant "helps somebody do something, or takes charge of some aspect."

To give care is "to take responsibility for a personal need" or "give comfort."

A caregiver "offers assistance and comfort, and makes life good."

You need to remember, I take pride in my abilities and accomplishments. Too much "assistance" and "caregiving" when I don't need it, makes me helpless and angry. The LESS you do for me, the more independent and successful I am in living my own life.

Your Roles: Hands-Off, Facilitator, Assistant, Caregiver



1. Hands-Off



2. Facilitator



3. Assistant



4. Caregiver

1. You can be HANDS-OFF

When you allow me to be independent and take whatever time I need to finish the task by myself. This is harder for you, than it is for me. Have patience!

2. You are a FACILITATOR

When you offer me encouragement, giving me cues, or teaching a skill.

Orientation Consistency Training

- I want to be the same person every day of the week, no matter who is with me or where we are.



NINE STAFF – ONE LIFE

Checklist: QA & Staff Evaluation

AGENCY CHECKLIST

- Did you show up?
- Keep to schedule
- Address goals
- Paperwork all done
- Training up to date

GANNET'S CHECKLIST

- Living life MY way?
- Facilitated so I could be as independent as possible?
- Allowed enough time?
- Was I given opportunity to speak?
- Staff a cell phone junkie?

PCP - Part 2

Task Analysis & Training

Setting the Table: Task Analysis

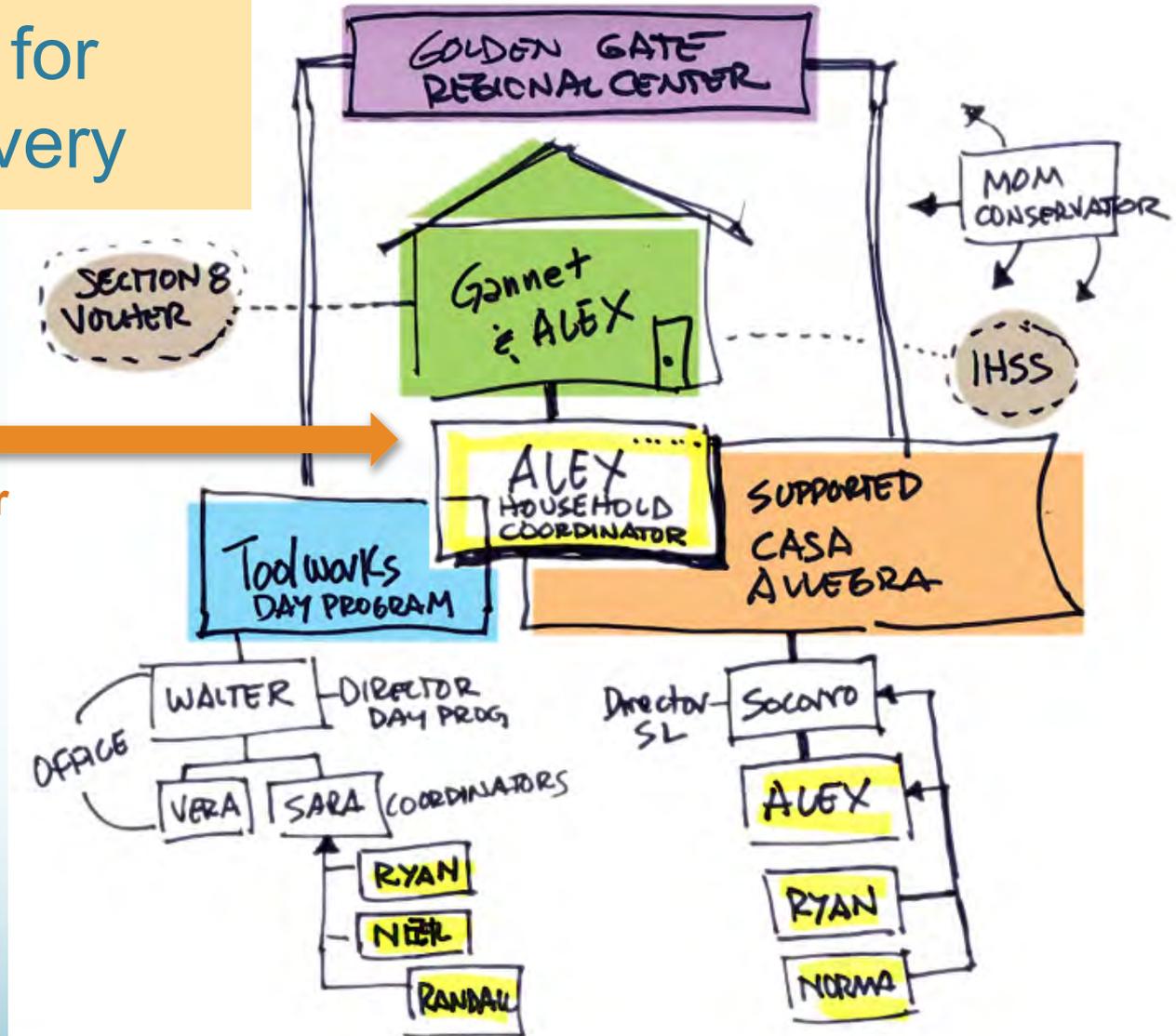
- The next step is to have Gannet get his own drink.
- Using verbal prompting such as *"Gannet, can you open the refrigerator and get your drink"*, Gannet will open the door.
- Gannet might have to be physically oriented so he faces the inside door.
- Using verbal and visual prompting Gannet will grab the drink and close the door.
- It does help to keep drinks on the far right of the bottom tray.



PCP - Part 3 New Model for Service Delivery

NEW POSITION Services Coordinator

- Direct supervision of Supported Living staff **on site**
- Interface between BOTH agencies



PCP Review

- It's MY life
- Defines preferences
- Explains how to achieve what I want
- Highlights MY skills
- Staff expectations
- Offers tips
- Covers issues
- Consistency
- Orientation, training

Benefits

GANNET

- Make my own choices
- Life can't be hijacked
- Live a full, meaningful life

ADULT AGENCY STAFF

- Orientation and training
- Gain respect for G's unique preferences

FAMILY

- No guarantees
- Gives G's life an anchor
- Parents can let go, and get on...